

# Alzheimer's Disease and Related Disorders



## *A Guide for Caregivers*



**Home and  
Community Services  
Aging and Adult  
Services  
Administration**

Washington State  
Department of Social  
and Health Services

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# Description of Alzheimer's Disease and Related Disorders

Alzheimer's disease (AD) is the most common form of dementia. Often called a "silent epidemic," it affects four million Americans. In Washington State, an estimated 65,000 people have Alzheimer's disease.

Dementia is the loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning for at least six months. The most common symptom is short-term memory loss, or forgetting what has happened minutes to days before. Poor judgment, difficulty with language, and a change in personality are other symptoms which may be present. Since short-term memory is the first to go, while long-term memory persists, the individual may be repetitious in asking questions or telling stories and may appear to be living in the past.

Usually striking older persons, Alzheimer's disease can attack in the middle years as well. Victims suffer a slowly declining ability to remember and loss of intellectual abilities. Physical disability follows as the disease progresses.

The disease was first described in 1906 by Alois Alzheimer, a German neurologist whose middle-aged patient developed memory problems, then severe dementia, and died at age 51. Much about the disease remains a mystery today. There currently is no known cause or cure.

Senility is a less preferred term for dementia, as it implies that confusion in an older person is a normal part of aging. Dementia is an abnormality at any age.



# Some Facts About Alzheimer's Disease

Alzheimer's disease is:

- a frequent cause of irreversible brain failure (dementia), that accounts for more than 60 percent of all dementia cases.
- the fourth leading killer in the United States, behind heart disease, cancer and stroke.
- generally, but not always, a disease of older people. The disease occurs in 10 percent of those over age 65 and 45 percent of those over age 85.
- a disease with symptoms that vary from patient to patient and from day to day in the same patient.
- a slowly progressing disease, averaging about eight years from the onset until death. The time can range from two to 20 years, depending on the age and other health factors of the individual.

Alzheimer's disease is **not**:

- insanity or “craziness.”
- contagious.
- “hardening of the arteries.” The disease associated with arteriosclerosis is stroke. Strokes are the second most common cause of brain failure.
- willful disagreeableness by the impaired person. Sufferers are sometimes wrongly thought to be acting deliberately when they display annoying behavior.
- simply the result of old age. Alzheimer's and other forms of dementia are the result of a disease process, and though more common with advancing age, they are not a normal part of growing older.

## ***Causes of the Disease***

The cause of Alzheimer's disease is unknown. It appears that acetylcholine and other chemicals in the brain play a role in Alzheimer's disease.

Exposure to aluminum and dental fillings have been mentioned as possible causes, but current evidence does not support these theories.

Genetics appear to play a role, especially in families where many relatives have Alzheimer's disease. Researchers continue to study these and other possible causes of Alzheimer's disease. The University of Washington Alzheimer's Disease Research Center is one of the leading research institutions in the country for studying this form of dementia.



## Other Dementias

Dementia is a general term indicating brain dysfunction characterized by loss of intellectual functioning. Some kinds of dementia, such as Alzheimer's disease, are irreversible; other types can be treated. A careful medical evaluation is needed to establish the cause of dementia.

### **Irreversible Dementia**

#### ***Multiple Strokes***

Micro-vascular disease, also known as multi-infarct disease, is the second most common cause of irreversible dementia after Alzheimer's disease. This dementia is caused by small strokes within the brain. While larger strokes are very obvious, small strokes may go unnoticed. However, over a period of years, many small strokes can mimic Alzheimer's disease.

Symptoms of micro-vascular disease vary, depending on the area of the brain affected. The disease may progress in a step-down pattern with a noticeable decline after each stroke.

It is possible for an individual to have a combination of micro-vascular disease and Alzheimer's disease.

#### ***Other Irreversible Dementias***

Alzheimer's disease accounts for 60 percent of all dementias and strokes account for another 20 percent.

Other causes of irreversible dementias include:

- A period of severe restricted blood flow or lack of oxygen to the brain caused by blood loss, shock, cardiac arrest, or carbon monoxide poisoning;
- End stages of some chronic diseases and conditions such as Parkinson's, Huntington's disease, multiple sclerosis, and Down's syndrome;
- Severe head trauma;
- Chronic alcohol or drug abuse;
- Rare neurologic diseases such as Pick's and Creutzfeldt-Jakob's diseases.

## Reversible Dementias

The following can cause dementia which may be, at least, partially reversible:

- Severe depression;
- Improper use of many drugs, particularly sedatives and alcohol;
- Interaction of multiple drugs, either prescribed or over-the-counter, or both;
- Hormone deficiency, especially a prolonged severe low thyroid;
- Increased pressure on the brain from bleeding (hematomas), tumors, or blockage of the flow of cerebrospinal fluid (hydrocephalus);
- Severe blood sugar disorders, such as diabetes;
- Severe vitamin deficiencies.



You should be aware that depression often accompanies dementia.





# Symptoms and Progression of Alzheimer's Disease

Alzheimer's disease does not have clearly defined stages. Usually, there is a slow, steady decline, but there can also be a rapid decline or periods of stability. Eventually persons will lose all physical and mental abilities to care for themselves.

## ***Symptoms Involve Problems With:***

**Memory** — Memory of recent events and learning ability become progressively impaired. Increased forgetfulness is often taken to be “normal” for an older person. Missing appointments, failing to pay bills, not recognizing acquaintances and getting lost in familiar places are **not** normal signs of aging. Mild memory changes may occur with aging but when memory impairment interferes with daily life, something is wrong.

**Behavior** — Symptoms can include repetitive questions, irritability, overreacting, night wakefulness, wandering, restlessness, inactivity, hostility, suspiciousness, unsafe actions, resistance to bathing, and problems with eating.

### **Daily**

**Activities** — Difficulties with routine tasks such as tying shoes or operating appliances are common. Late in the disease the person can develop difficulty in walking, dressing, eating and bathing, and may become incontinent.

**Language** — Increasing difficulty with communication may become evident. The person might not be able to follow directions, find the right word, participate in conversations, or understand written material.

**Judgment** — Safety issues around driving, leaving burners turned on, and locking oneself out of the house become

major areas of concern. Other judgment issues may involve less critical behaviors such as choosing inappropriate clothing for the weather or occasion.

### ***Progression of Alzheimer's Disease***

A common early sign is forgetfulness, especially of recent events. Memories of the distant past usually remain clear. The person may seem to have less drive and initiative and be slower to react and learn. The family may not be sure anything is wrong and the person may cover up problems and seem more capable than he or she really is.

Losses continue as the disease progresses. Problems with judgment and comprehension may be noted and language problems may become more evident.

The ability to understand what one hears—to follow a conversation, for example—may be affected. Planning ahead and making decisions become difficult.

As the disease progresses, Alzheimer's victims experience obvious disability. The person may be disoriented, that is, not know where he or she is or what day it is. The person may be unable to recognize familiar people or places.

Physical deterioration continues and the person may become bedridden and need help with all activities of daily living. Difficulty in swallowing may also be evident. Because of inactivity and physical deterioration, pneumonia is often the cause of death.



## Medical Evaluation and Treatment

### *How a Diagnosis is Made*

The physician will do a complete examination and an assessment of mental and psychological status. The physician will look for treatable (reversible) conditions, such as depression or drug interactions, which might be causing the memory loss. Such causes, if discovered, will then be treated to see if the dementia improves.

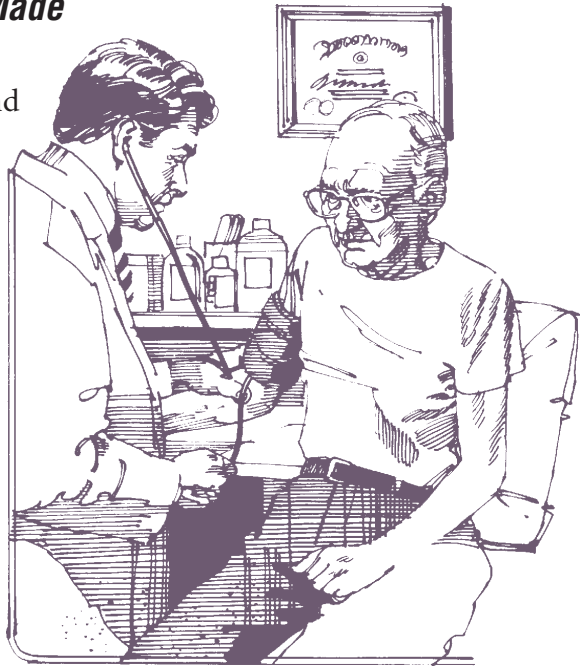
The physician will work with the person and his/her family to determine whether there has been a gradual, progressive loss of intellectual functioning that has persisted for six months or more. Social history should also be determined.

A number of tests and examinations may be performed, such as CAT scan (computerized x-ray) or detailed examination by a neurologist. Neurological examination will give the physician information about the brain, spinal cord, nerves and muscles.

A mental status test is usually done to determine the extent of the person's intellectual and memory impairment.

If no other cause of the dementia can be found, Alzheimer's disease is the likely explanation. This ruling out process is the only way to identify Alzheimer's disease prior to death. It is 80-90 percent accurate.

A microscopic examination of the brain after death is the only method of confirming the diagnosis of Alzheimer's disease.



Early in the disease the person may seem quite normal to the physician. It is vitally important that relatives tell the physician what they have been noticing that indicates something is wrong. A discussion with the physician will help the family—and, as much as possible, the patient—understand findings of the evaluation and its implications for future planning.

## ***Medical Treatment***

Medications cannot stop the progress of the disease, but they can *sometimes* ease the symptoms such as night wakefulness, agitation or the depression associated with some Alzheimer's cases. It is important that correct dosages, adjusted for the patient's weight and age, be prescribed and that drug effects are monitored closely. Techniques to control behavior rather than relying on prescription drugs may avoid undesirable side effects of medications.

## ***General Health***

The goal of all care is to provide for safety and keep the person's intellectual and physical functioning as high as possible for as long as possible. Adequate exercise and a nutritious, well-balanced diet will help maintain the person's general health.

## ***Providing Supportive Care***

Patients also need understanding and support to help them cope with their frustrations and emotions. Particularly in early stages of the disease, many patients realize they can no longer remember or perform tasks as they once did. Thus, they may feel frustration, anger, or fear and need assurance from those around them.

Sometimes the most effective method of dealing with problem behavior is to modify the patient's environment or change the caregiver's response to the behavior. Often you can't change the patient's behavior but you can change your own.



# Caregiving – Some Common Problems and Possible Solutions

## ***Tips for Direct Care***

Since the person's abilities to learn and change are limited, those around them must adapt and keep expectations realistic. The confused person will be most at ease in familiar surroundings. Consistency in daily routine and attitude helps.

Tasks can be simplified if making choices has become difficult. A calm and orderly atmosphere reduces agitation. Use of repetition and memory aids help prolong self-sufficiency. Understanding the person's moods is important, since reasoning will not work. Gentle persuasion and nonverbal communication may help.

It is important to spend quality time with the patient, reminiscing, offering reassurance and praise when appropriate. Encourage laughter and maintain a sense of humor. Everybody will benefit. Above all, treat the patient as an adult.

## ***Nutrition and Meals***

Calm, unhurried meals with food served in easy-to-handle ways help keep the person relaxed. If poor coordination leads to messy eating, adaptations like plastic table covers or a cover-up smock are useful. Cutting food or plates with raised rims may help. Food and beverage temperatures should be checked, because the person may be unable to judge safe temperatures. A light snack may satisfy the person who cannot remember eating and asks again for food.

Watch for any swallowing difficulties and report them to the physician or health care professional.

## ***Hygiene***

It is important to understand the feelings and needs for privacy of people who cannot care for themselves. Make bathing and dressing easier (put out only the clothes to be worn, for example) and follow as many of the person's old patterns as possible. For safety, check

water temperatures and remember that a confused person should not be left alone in the tub or shower.

## ***Incontinence***

Report incontinence (the inability to control bladder and bowel elimination) to the physician to learn if the condition can be treated. It may help to remind the person at regular times to use the bathroom or actually walk with them to the bathroom, and to learn when the person with language problems is asking for help. If necessary, you can use adult disposable briefs and protective coverings for the bed and furniture.



## ***Exercise***

Exercise can help the person stay calmer, sleep better, and retain motor skills. Some ideas are walking, dancing, doing exercises in a group or playing at sports enjoyed earlier. Even in the late stages of the disease, encourage and assist the person to walk. This will prevent unnecessary health problems.

## ***Recreation***

Persons with dementia enjoy many recreational activities. Music, selected television, visiting old friends, or looking through magazines are possible choices. Eating out may be enjoyable if the person has retained social skills. Gardening, walking and adapting old hobbies to meet current skill levels are all good recreational choices.

## ***Safety***

A person who no longer comprehends danger or who is physically impaired needs safety precautions. Examples are grab bars and nonskid mats in the bathroom, night lights, removing clutter to

prevent falls, sturdy handrails on stairs, or gates at tops of stairs. Also watch out for hazards such as smoking or unsafe use of appliances. A confused person should not drive a car, use power tools, or have access to firearms.

## ***Wandering***

It's not always possible, but if you find the cause for wandering (disorientation in a new place, restlessness or a need for exercise), you can help control it. Introduce the person to a new environment gradually while reassuring of whereabouts to lessen disorientation. A person who wanders should wear an identification bracelet with name, address, phone number, and medical condition.

## ***Sleep Disturbances***

Daytime activity, adequate exercise and using night lights to reduce confusion in the darkness could ease nighttime restlessness. However, the disturbance may result from inability of the body's "clock" to tell night from day. In extreme cases, medications may sometimes need to be prescribed to reduce frustration and encourage sleep.

## ***Depression***

Depression can complicate the problems a person experiences with Alzheimer's disease. It is important to pay attention to symptoms of depression including sadness, loss of interest in people and activities, sleep or appetite changes, and thoughts of death or suicide. Maintain pleasant activities and social contacts to help prevent depression. If you do suspect depression, discuss it with your physician or another health care professional.

## ***Agitation***

A calm, well-organized daily routine helps decrease agitation. Fatigue, confusion, hunger, or physical illness are a few causes of increased agitation. It is important to observe and identify possible triggers of agitation for each individual. Identify the "early warning signs" of agitation; intervene by distracting, reassuring, or modifying the situation before the person becomes extremely disturbed.



## Some Guidelines for Taking Care of the Caregiver

It is not easy to care for a person who has a dementing illness. Caregivers must realize they are not super-people—they are human. The caregiver may feel sad, discouraged, frustrated, angry, or trapped. These are all natural feelings and they can be dealt with in a positive way.

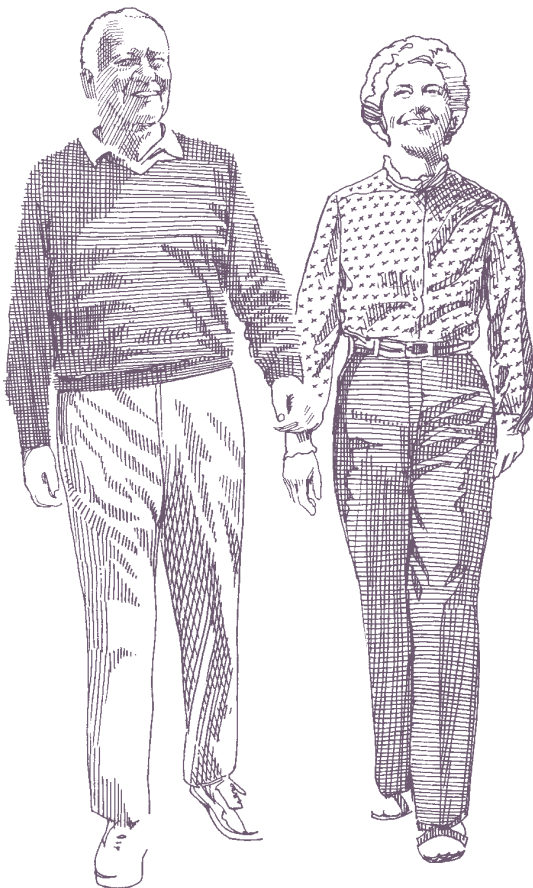
Caregivers must take care of themselves as well as their patients. It is all right to ask for and accept help. There are many sources of help and information both inside and outside the family.

### ***Take a Break!***

A regular break from caregiving is essential. It allows a caregiver to rest physically and emotionally. It is as important to health as diet and exercise, and it is not selfish.

Caregivers need to get enough rest, continue to enjoy their own friends, and make an extra effort to maintain physical and mental health through good nutrition.

Incontinence, wandering and sleep disturbances are the most common problems





associated with nursing home care. These same problems confront caregivers at home and often result in the caregiver not being able to manage alone or becoming ill. Getting away—taking a “respite”—benefits both the caregiver and the impaired person.

Consider using family members, friends, neighbors, fraternal and church associates, or college and nursing students for help and to get a break from caregiving. Taking a break generally requires frankness. Family members and others not directly involved in the care of the dementia patient may not realize the demands the caregiver faces.

Many communities have adult day care or in-home respite care services. Some nursing homes also may offer adult day care and short stays for elders.

Ideally, a respite care provider who comes to the home should make one or two get-acquainted visits while the permanent caregiver is there, too.

The following information should be given to respite care providers:

- Emergency telephone numbers
- How to reach the caregiver
- Estimated time of the caregiver’s return
- Special instructions in caring for the impaired person and managing difficult behavior.

Be honest about any problems—sooner or later a substitute care provider will confront difficult behavior.

## ***Maintain Important Relationships***

Caregivers can easily become isolated because of their responsibilities. It’s important to build and fortify relationships early in the disease. Family and friends can be a source of great comfort, help, and pleasure.

## ***A Support Group Can Help***

Support groups for families of Alzheimer’s victims can be a tremendous source of understanding, resources, and information.

Contact one of the Alzheimer's Associations listed below to learn about the support groups near you.

## ***Find Out More Information About Alzheimer's Disease***

If a dementing illness is diagnosed, everyone involved in the support and care of the patient will benefit from knowing as much as possible about the disease. Knowing what to expect and how to deal with behavioral changes helps family, friends, and caregivers to understand and accept the patient, plan for the future, and set realistic expectations. Unrealistic expectations increase anxiety and agitation in the patient and stress for the caregiver.

Don't hide. Alzheimer's is a disease, not a crime. Although explaining the disease to others may be difficult, it helps family, friends, and neighbors understand the patient's behavior and the stress of caregiving.

The National Alzheimer's Association is a non-profit organization whose purpose is to support caregivers, promote research, provide public education, and advocate for public policy affecting AD patients. The Alzheimer's Association of Western and Central Washington State, located in Seattle, is a local chapter of the national organization. This chapter provides local resource information and referral, free literature, sponsors support groups in a 22-county area, and publishes a quarterly newsletter. The Eastern Washington chapter also provides resource information and a quarterly newsletter, and sponsors support groups. To contact these organizations:

Alzheimer's Association of Western and Central Washington State  
1422 N.W. 85th Street  
Seattle, Washington 98117  
206-783-6600 or toll-free 1-800-848-7097

Alzheimer's Association, Eastern Washington Chapter  
North 5125 Market  
Spokane, Washington 99207  
509-483-8456

National Alzheimer's Association  
919 North Michigan Avenue, Suite 1000  
Chicago, Illinois 60611  
1-800-272-3900

The Alzheimer's Society of Washington is an independent organization serving Washington State. The Society offers training, advocacy for AD patients and families, and resource materials. To contact this organization:

Alzheimer's Society of Washington  
P.O. Box 4104  
Bellingham, Washington 98227  
360-671-3316

### ***Keep Commitments Realistic***

Caregivers need to consider what is best for themselves and the family, as well as the memory-impaired person. Nearly everyone has made an emotion-laden promise based on an unknown future. (Promising never to place a family member in a nursing home is one of the most common.)

There may come a time when nursing home care is best. This is often a difficult decision. The Alzheimer's Association offers these guidelines to decide about placing a memory-impaired person in an adult family home, Adult Residential Care or Assisted Living facility, or nursing home:

- If a memory-impaired person wanders severely; or
- cannot be safely cared for at home; or
- has health needs that cannot be met at home; or
- presents a danger to self or others; or
- is unable to care for self in the most basic ways; or
- frequently interrupts another's sleep; or
- caregiver's health is endangered.

Unforeseen circumstances make it impossible to keep some promises. Realistic commitment does not include words like “always,” “never” or “forever.” Old promises or guilt must not guide decisions the caregiver must make. What is important is that the person receives the best care possible in a safe environment.

## ***Do Something Nice For Yourself***

An occasional self-indulgence can be amazingly helpful in coping with stress. Some people may buy themselves “presents”—a magazine or a new dress—listen to a symphony or a ball game, stand outside and watch the sunset, or order a favorite restaurant meal as a carry-out. Other simple but enjoyable activities might be just talking to a friend or reading a book. The list is endless, but it is important to remember how beneficial this can be.

## ***Recognize the Warning Signals of Stress and Get Counseling***

Everyone has ways of responding to stress and problems. What is a healthy response from one person may be unhealthy for another.

The caregiver should ask:

- Do I feel sad or depressed that I am not functioning as I should?
- Am I lying awake at night worrying?
- Am I losing weight?
- Do I feel overwhelmed most of the time?
- Do I feel terribly isolated and alone with my problem?
- Am I drinking too much?
- Am I losing control of my emotions?

If the answer to some of these questions is yes, the caregiver may be carrying too heavy a burden.

Anger and frustration are normal when caring for a person whose behavior is difficult. If the caregiver appraises his or her response to the situation honestly, there are people and groups who can help.



## Legal and Financial Considerations

Caring for a dementia patient requires planning—the earlier the better. It is essential to plan for the possible financial impact of the illness and explore available legal options. When facing long-term illnesses such as Alzheimer's disease, it pays to understand the cost of various long-term care options, to learn what financial assets the person has and what benefits may be available to them, to decide if or when property or other assets should be transferred, and to enable someone to make decisions for the person when that becomes necessary.

Possible sources of benefits include insurance policies, Social Security, Supplemental Security Income, or veteran's benefits. Persons supporting or paying medical expenses for a dependent may also be eligible for tax deductions.



You can find information from the local Senior Information and Assistance Program, a local caregiver support group, or an attorney who has experience in elder law and health-related issues.

## ***Legal Strategies for Managing Health Care***

It usually will be necessary at some point during the disease for someone to make health care decisions on behalf of the dementia patient. Plan for this time by discussing with the patient, as soon as possible, what level of medical treatment is desired and to establish an appointed surrogate (substitute) decision maker. This surrogate can ensure the patient's wishes are carried out after the patient is unable to do so. It allows the patient to retain some autonomy over his or her life despite the progression of the illness.

A mentally competent individual can decide in advance how personal health care decisions are to be handled through the following directives:

**Living Will or Health Care Directive** – This legal document directs the doctor that, in the event that a person becomes terminally ill and further treatment will only delay the moment of death, not to use artificial life supports. It requires two physicians to certify a disease is incurable before allowing treatment to be withheld.

**Durable Power of Attorney for Health Care** – a legal document that allows another person to make medical decisions for someone who has lost the ability to make their own decisions. It can include detailed specifics for caregivers stating clearly what should be done in the way of treatment and life-sustaining supports. It allows a trusted friend or family member to direct the physician in honoring the patient's wishes.

The person executing these directives can change or revoke them at anytime.

**Informed Consent** – If there are no advance directives, the informed consent law goes into operation. Health care providers must seek health care decisions from the first available class of surrogate decision makers. In descending order of priority the classes are: guardian, agent in a durable power of attorney for health care, spouse, adult children, parents, and siblings. A decision must be unanimous among all available members of that class. If not, a guardianship must be obtained.

## ***Legal Strategies for Managing Finances***

Although Washington is a community property state, it is always important to make a will or keep an existing one regularly updated. Other steps taken will be influenced by the situation and the patient's degree of impairment. As in health care decisions, the patient's autonomy should always be a primary objective. Some strategies to consider include:

**Durable Power of Attorney** – a legal document signed by a competent person which gives another person the authority to handle some or all of the first person's affairs. Unlike an ordinary power of attorney, a durable power of attorney continues to operate even after the person granting it becomes incapacitated.

**Protective Payee** – an arrangement where government agencies that pay benefits can appoint someone to receive and disburse the benefit payments on behalf of a recipient who is no longer able to manage financial affairs.

The Social Security Administration calls this a "representative" payee, while the Washington Department of Social and Health Services uses the term "protective" payee. The Department of Veterans Affairs and Railroad Retirement Board have similar provisions. These payee appointments are made administratively rather than through a judicial process.

**Trust** – a transfer of money or property to one person (trustee) for the benefit of another (beneficiary or maker). The trust is managed by the trustee until some date or condition is met. A trust may not be worthwhile unless the maker's assets are substantial. Trusts are complicated and expensive to set up and administer.

**Money Management Alternatives** – a number of limited arrangements that can help a person handle specific kinds of financial transactions. Alternatives might include banking services such as direct deposit banking, automatic banking where the bank will pay regular bills, or hiring a personal bill paying service. These work best for those who function well on a daily basis but need a little help with small financial matters.

**Guardianship** should be considered an option only as a last resort. A guardianship is a legal process that allows an individual (or

organization) to make decisions for a person who is no longer able to do so. A guardianship is established only through a court proceeding.

Under Washington law, either a “full” or “limited” guardian can be appointed, depending on the extent of the impaired person’s incapacity and documented abilities. Under limited guardianship, the incapacitated person retains all rights except those specifically assigned to the limited guardian. A guardian can be responsible for financial decisions as well as health care decisions.





## Paying for Care

Besides private purchase of care and other services, there are programs that help pay costs of in-home and residential care for people who qualify because of income or other reasons. These programs are discussed briefly below. Additional information is available from local Senior Information and Assistance, DSHS Home and Community Services offices, or Medicare offices.

### ***Medicare***

Medicare is a federally-funded health insurance program for people 65 and older, as well as for some people under the age of 65 who are disabled.

When program requirements are met, Medicare will pay for the following:

#### ***Part A will pay for :***

- medically-necessary inpatient care in a hospital, skilled nursing facility, or psychiatric hospital
- hospice care
- medically-necessary home health care
- part of the approved cost for durable medical equipment covered by the home health benefit.

#### ***Part B helps pay for:***

- medically-necessary physician services at home, in the doctor's office, in a clinic, or hospital
- related medical services and supplies
- medically-necessary outpatient hospital services
- x-rays and laboratory tests
- certain ambulance services
- in-home use of durable medical equipment, such as wheel-chairs and hospital beds.

Medicare, however, has limits on the length of time and the circumstances under which it pays for care. Medicare covers only

“reasonable and necessary” care and does not cover custodial care (care that helps with activities of daily living).

Contact a Social Security Administration office for a Medicare application and more information about the program. You can find the number in the government section of the phone book under the “United States” section.

## ***Medicaid***

Medicaid is a state/federal program that pays for some long-term services. Medicaid will pay in-home, residential, and nursing home care costs if the patient meets program eligibility and financial need requirements.

### **Program Eligibility**

Apply for services is through your DSHS Home and Community Services (HCS) Office. You are entitled to apply in person or by mail and receive a written decision on eligibility within 45 days. If you disagree with the decision, you may ask for a Fair Hearing review. Ask the case manager for help with this. (See page 25.)

### **Financial Eligibility**

The financial eligibility rules for Medicaid are very complex and subject to change. Financial rules protect the finances of spouses of persons receiving assistance. Spouses may keep significant amounts of both assets and income. Ask the case manager for more information.

### **Estate Recovery**

State and federal law require the recovery of Medicaid funds and state long-term care funds from a deceased recipient's estate. After a recipient dies, there may be a claim against their estate for the benefits the person received.

When a recipient is survived by a spouse, the state can recover funds only after the death of the surviving spouse.

## ***Veterans Benefits***

A wartime veteran or surviving spouse (married at time of veteran's death) may be eligible for a pension through the State's Department of Veterans Affairs (VA). Also, the dependent parent of a veteran killed in service or who dies of a service-connected disability may be eligible for VA Dependency and Indemnity Compensation.

If there is any relationship to a veteran, call the Department of Veterans Affairs for more information. The toll-free number is 1-800-562-2308.

## ***Long Term Care Insurance***

Some people have long term care insurance that pays for home and community services and nursing home services. Check the policy carefully to see what, if anything, related to Alzheimer's disease is covered.



# Community and Residential Services

## ***How to Get Help***

### **Home and Community Services (HCS) Office**

The HCS office in your area can help if you are considering nursing home or other residential care or in-home services. The number is listed in the telephone directory under “Washington State Department of Social and Health Services,” in the Yellow Pages under “Senior Services” or “Disabled Services,” or you may call the toll-free HelpLine **1-800-422-3263** to locate the office nearest you.

Professional case managers and nurses have information about in-home community and residential services. They will complete an assessment of service needs and will assist in the decision about appropriate services. They can authorize in-home services, Adult Residential Care, Adult Family Home, Assisted Living, and nursing home care for eligible persons.

### **Senior Information and Assistance**

Senior Information and Assistance (I&A) offices, located throughout the state, are usually listed in the telephone directory Yellow Pages under “Senior Citizens Service Organizations.” Or you may call the toll-free HelpLine **1-800-422-3263** for the office nearest you. I&A offices serve people 60 years of age and older.

I&A staff are knowledgeable about in-home, community and residential services, the cost of services and whom to contact about them. They can help obtain services by assisting with forms, arranging for transportation, and advising you of benefits. Consult an I&A office before deciding on nursing home care. There may be community services or other types of residential care available to meet the person’s needs.

## ***What Community Services Are Available***

A number of services are available to adults at no charge or a reduced fee. Call your Home and Community Services Office or Senior I&A office; they can explain which of the following services are free or take donations and which have fees based on ability to pay.

## **Adult Day Care/Adult Day Health**

Social activities, therapies, health education and supervision are provided in a group setting during the day in facilities such as churches, nursing homes, and community centers. (Not available in all communities.)

## **Adult Protective Services**

Investigation of alleged abuse, neglect, exploitation, or abandonment, and short-term emergency support services to adults in need of protection.

## **Case Management**

Comprehensive assessment of individual needs and development of a detailed plan of services. Ongoing follow-up to make sure services are provided.

## **Health Screening (age 60 or older)**

These preventive health measures include a general health assessment, limited physical examinations and selected laboratory tests. (Not available in all communities.)

## **Home Health**

In-home health care (monitoring, treatments, medications, exercises) authorized by a physician and provided by nurses, therapists, or trained aides.

## **Hospice**

Medical services, home care, social services, and counseling to terminally-ill patients and their families. (Not available in all communities.)

## **Information and Assistance (age 60 and older)**

Specialized information about senior services available in the community and help obtaining needed services.

## **Mental Health Services**

Evaluation of the need for mental health services and emergency and outpatient treatment. Check in the Yellow Pages of the telephone directory, under the headings of Mental Health Services or Social Service Organization.

## **Minor Household Repairs**

Home or apartment repairs or modifications needed for health and safety. (Not available in all communities.)

## **Personal Care**

We can arrange for help with personal care tasks such as bathing, dressing and grooming, meal preparation, and household chores. Personal care is designed to help the client continue to live safely at home.

Eligibility is determined by income, resources and care needs. People with higher incomes can purchase services privately, and some services are available through volunteer programs.

## **Respite Care**

This provides relief for caregivers of adults with disabilities. Respite services can be arranged through home health agencies, Adult Family Homes, Adult Residential Care, social day care, nursing homes, or family, friends and volunteers.

## **Senior Centers**

Community facilities where older people can meet, receive services, and participate in activities.

**Senior Meals** (age 60 or older or if spouse is 60 or older)

Nutritious meals and other dietary services provided in a group setting or delivered to home-bound persons.

## **Transportation**

Rides to and from social services, medical services, meal programs, senior centers, shopping and recreational activities.

## ***What Residential Services Are Available:***

### **Adult Family Homes**

An Adult Family Home is a residential home licensed to care for up to six adults. Services include room, meals, laundry, necessary supervision, personal care, and social services. Nursing services may be provided.

Certain homes specialize in the care of dementia-related disorders and offer activities and assistance designed to meet the needs of this client group.

### **Adult Residential Care (ARC) (formerly Congregate Care)**

Room, meals, laundry, limited supervision, and help with personal care in a licensed boarding home. Facilities house six or more persons with some boarding homes housing over 200 occupants. Like Adult Family Homes, some ARC specialize in particular client groups and also help with medication and health care.

### **Assisted Living**

Assisted Living offers private apartments. Services are available on a 24-hour basis to accommodate each resident's needs and abilities. These services include meals, personal care, help with medication, organized activities, limited supervision, and limited nursing services.

The Assisted Living program emphasizes privacy, independence, and personal choice.

### **Nursing Homes**

Licensed nursing homes provide 24-hour supervised nursing care, personal care, therapy, supervised nutrition, organized activities, social services, room, board, and laundry.

In Washington State, there are many nursing homes with Alzheimer's units. These units provide for the special needs of the Alzheimer's resident. Staff are trained to assist residents to maintain their self-care abilities as long as possible.

Alzheimer's units frequently have enclosed exercise areas outside, track-like areas for walking inside, and activities geared for the resident with a short attention span.

### ***After a stay in the nursing home...***

Many people enter a nursing home for rehabilitation or short-term intensive nursing care. Nursing services and personal care can also be provided outside of a nursing home, either in a private home or in a community setting. Planning for care after the nursing home should begin as soon as possible.

Home and Community Services (HCS) social workers and nurses can help with the following:

- describe service options;
- develop a plan to allow functioning at the highest level of independence;
- work with other service providers in the community; and
- determine eligibility and arrange services to support independence.

### **Income Exemption**

If a nursing home resident is likely to return home within six months, they may keep some part of their income to retain their home or apartment. The physician must certify the probable return home.

### **Discharge Allowance**

A one-time discharge allowance can help a resident find a place to live and set up housekeeping after a stay in a nursing home.

For more information, ask the Home and Community Services case manager.

### ***Complaints and Concerns ...***

If you have complaints about care in Nursing Homes, Adult Family Homes, or state-contracted Assisted Living and Adult Residential Care, you can call Aging and Adult Services Administration at 1-800-562-6078. This call is toll-free and confidential. The TDD number is 1-800 -737-7931.

If a resident in any of these settings needs help resolving a care or service problem, you can call the State Long-Term Care Ombudsman toll-free at 1-800-562-6028.



## *Announcing a new video –*

# *Options:* You Have a Choice

Aging and Adult Services Administration has a new video that will show you the services in this brochure.

To see *Options: You Have a Choice*, ask your case manager or call 1-800-422-3263. There is no charge to borrow the 15-minute video.

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The information in this brochure is available in alternative formats.

This brochure was produced by Washington State Aging and Adult Services Administration, Department of Social and Health Services. Special thanks go to:

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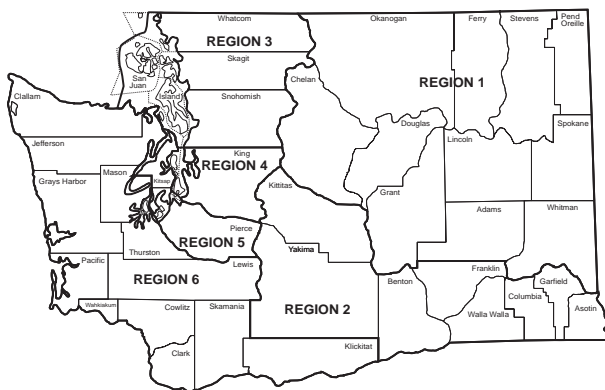
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Social and Health Services Warehouse  
P.O. Box 45816  
Olympia, WA 98504-5816

or FAX : (360) 664-0597



## ***Home and Community Services Regional Offices***

Region 1 Spokane, Grant, Okanogan, Adams, Chelan, Douglas, Ferry, Lincoln, Stevens, Whitman, and Pend Oreille Counties  
1-800-459-0421 or (509) 323-9400

Region 2 Yakima, Kittitas, Benton, Franklin, Walla Walla, Columbia, Garfield, and Asotin Counties  
1-800-822-2097 or (509) 575-2006

Region 3 Snohomish, Skagit, Island, San Juan, and Whatcom Counties  
1-800-487-0416 or (360) 428-1434

Region 4 King County  
1-800-346-9257 or (206) 587-5620

Region 5 Pierce and Kitsap Counties  
1-800-442-5129 or (253) 593-6164

Region 6 Thurston, Mason, Lewis, Clallam, Jefferson, Grays Harbor, Pacific, Wahkiakum, Cowlitz, Skamania, Klickitat, and Clark Counties  
1-800-462-4957 or (360) 438-8840

### ***Aging and Adult Services Administration***



P.O. Box 45600  
Olympia, Washington 98504-5600  
Toll-free 1-800-422-3263 or TDD 1-800-737-7931  
TDD: (360) 493-2637

